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Disability Policies in France: Changes and Tensions between the Category-based, Universalist and Personalized Approaches

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ABSTRACT *In this article, the authors show that the current French disability policy is traversed by conflicts between three different approaches to disability which came about at different periods in history. They begin by looking at the origins of disability policy in France. This policy was developed during the 20th century, from notions of repair, indemnification and compensation through rehabilitation. It became institutionalized in 1975, when two laws were passed, giving it the form of a category-based policy. Between 1970 and 2000, affected by the international situation, this policy came into conflict with a universalist policy. More recently there has been a desire to develop a personalized approach. Finally, the authors use two examples (taken from recent debates on the implementation in France of the new law of 11 February 2005) to show the tensions that have led to the coexistence of these three approaches within current disability policy.*

Introduction

At an international level, over recent years disability policies have been marked by the gradual emergence of non-discrimination policies. At a European level, in 1997 the Treaty of Amsterdam included a non-discrimination clause in relation to disabled persons. In 1993, the United Nations set out the rules for equal opportunities for disabled persons, and they have just drafted an international agreement on the rights of disabled persons, which will enter into effect as soon as it has been ratified by all 20 countries. Such major international orientations are gradually making their mark on what we will call, in this article, the “social treatment” of disability, i.e. a set of views, practices and policies relating to disability. For over a century, France, with its welfare state traditions, has had legislation covering victims of work-related accidents and then maimed soldiers, before finally being generally

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applied in 1975 to all disabled persons, when two laws were passed: the “orientation law in favour of disabled persons” and the law governing social and medico-social institutions. These two laws established a disability policy in France, and created the status of “handicapped person”, by defining specific rights for such people, and by leading to the development of specialist or common law intervention devices. This entire policy is now undergoing in-depth changes. The 1975 law in favour of disabled persons has been replaced by a new law, of 11 February 2005, entitled the “law on the equal rights and opportunities, the participation and the citizenship of disabled persons”. This law changes France’s policy on disability inasmuch as it establishes new rights for disabled persons, changes the institutional intervention device and asserts the need for everyone to have access to everything. The drafting of the law required major negotiations between all actors involved in the problem: politicians, administrators, associations, scientists, etc. This process officially started in December 2002, and still continues today through the drafting of decrees governing application of the law and through the implementation of the new device. By bringing all actors together at the negotiating table, this process of revising and organizing a new policy gave rise to fruitful debates on both the conceptions of disability and the different types of “social treatment” for disabled persons. The questions under examination were both theoretical and practical: what is disability? Must we or can we define disability within the framework of a law? What must/can the relationship be between “society” and “disabled persons”? What might the objectives of a disability policy be? When referring to people who are sometimes very heavily disabled, what do the terms “citizenship” and “social participation” really mean? How can compensation and non-discrimination be combined? And so on. During these debates, the various actors were obliged to explain their standpoints – often the opposite of those of the other parties – on all of these questions.

France’s current disability policy is therefore the result of a political and administrative device that is loaded with history and which has evolved under the influence of the international situation. In this article we will be making a socio-political analysis of France’s disability policy. By looking back at the history of disability and at more recent debates surrounding the implementation of the new law, we will show that the field of disability is currently traversed by tensions between different types of treatment and different conceptions: a category-based conception, a universalist conception and an interactive and personalized conception.

The first part of the article looks at the historical changes which led to the implementation of the disability policy in France in the second half of the 20th century. We will then describe the emergence of these three conceptions and their related modes of treatment. We will show that they are linked, that they in some way call upon one another, and finally, that they coexist without replacing one another – even if within this evolution we can point out certain major shifts. In the third part, we will examine the tensions caused by this coexistence within the new policy. We will concentrate on two significant examples: the integration into the law of a definition of disability, and the

creation – through the law – of a new right, the right to compensation. We will demonstrate that this new disability policy is part of both continuity and severance. It integrates certain aspects acquired through history whilst at the same time making it possible to make changes for the people concerned.

The Historical Context, the Origins of Disability Policy in France

Infirmity as a Condition: between Assistance and Social Control

Throughout the Middle Ages, people with impairments – referred to as “cripples” – were considered to be part of a larger group, that of the “deserving poor” (Castel 1995, Stone 1984). This label covered anyone who was unable to work – not just the crippled, but the insane, old people, orphans, widows with a large family to provide for, etc. Because it was accepted that they were unable to provide for themselves through work, all these people could legitimately benefit from assistance and charity. There was also a certain hierarchy among the “deserving poor”. There were two reasons why the crippled had a privileged status. On one hand, their infirmities made their incapacity to work visibly and undeniably clear and independent of their wills. On the other hand, in the Christian condition, the suffering poor are exalted because they symbolize Christ’s suffering and allow the rich to gain salvation by being charitable. To this first criterion, that which allows the person to benefit from assistance (the recognized inability to work), a second can be added: domiciliation. In France, help is mainly provided by the Catholic Church, via the clergy and religious orders, to people within the parish. These two criteria – inability to work and domiciliation – allow one to distinguish between those who are helped and those who must work (Castel 1995).

This way of thinking about and organizing assistance was common to all western countries in the Middle Ages. From the 14th century, following changes in work organization and social structure, the question of helping the “deserving poor” was examined in the light of another question crucial to the times – that of vagrancy and the mobility of the workforce. In most European countries the number of vagrants was increasing. Vagrants were causing problems in pre-industrial society. On one hand, they were physically able to work, but circumstances meant that they were not able to integrate the traditional work structure. They were therefore forced to move around to find work elsewhere, and, while waiting to find work, to beg. On the other hand, they represented a threat to traditional work organization; where or when there was a lack of workers, they could negotiate their salaries or refuse to do the work that was offered. Consequently a negative image of vagrants came about, as they were seen as dangerous and useless. As far as the authorities were concerned, it was no longer a case of simply helping the poor, but also and above all of controlling and repressing vagrants, and preventing them from travelling. For Stone (1984), the roots of the administrative category of “disability” are found in the necessity to maintain a clear distinction between a distributive system based on need, and a distributive

system based on work, and thus on the requirement, as from the 14th century, to introduce devices with which to distinguish between vagrants who were legitimate because they were unable to work, and those who were not legitimate and ought to work. (Stone analyses the construction of the disability category by returning to the history of the Welfare State in three countries: England, Germany and the USA.) In England, the desire to control led to devices such as letters of authorization to travel (1388), which for able-bodied persons gave the reason for the journey in question, and for disabled persons they stated the type and duration of the disability; a system of identifying badges for legitimate beggars (1563), and to the generalization of workhouses and forced labour (1834). In France, it strengthened the practices of hospitalization and confinement, and, more particularly, to the development of the “general hospital”¹. The French Revolution was the beginning of a gradual shift from the notion of private charity to that of public charity. Under the influence of the philosophers of the Enlightenment, there appeared the idea that assistance was the duty of the State. In 1790, the principles of the “Comité de Mendicité” (a committee governing begging) were: assistance is a social duty, savings plans were a necessity, and private charity must be encouraged. But the first public aid establishments, created in 1796 by the Directory, took the form of charity offices which were communal services under the authority of Prefects. The result was that during the entire 19th century, the duty to assist was exercised at local level and was therefore optional (Stiker 1999). It was in 1905 that public assistance became a legal obligation in France for the elderly, crippled and incurable. This free assistance was aimed at individuals who were without resources and who could not work (“the deserving poor”). People who could work were expected to resort to personal funds in the form of savings, to protect themselves against insecurity and destitution.

Disability, Damage caused by a Collective Activity, Gives One the Right to Repair

At the end of the 19th century and at the start of the 20th century, two major events led to a change in the help given to the impaired and to the breakdown of the distinction between “good” and “bad” poor people: on one hand, industrialization and the resulting impoverishment, on the other hand, the First World War. The new working conditions which emerged from the successive waves of industrialization made it impossible for the majority of workers to guard against insecurity through individual savings (it is possible to work and still be poor). Furthermore, work accidents, which were common in this context, were a problem (Ewald 1986). France’s Civil Code did not provide for the indemnification of victims of work-related accidents, as the procedure required that it had to be proven to be the employer’s fault. Often it was impossible to find any fault that could be put down to a given individual, or when it was possible, it was difficult to prove it. The worker, victim and often invalid, remained without resources and without the possibility of finding a new job. Proceedings started by workmen, which had unsatisfactory outcomes for either the workman or the employer, led to an awareness and to

a debate in the national assembly that in turn led to the law of 9 April 1898 on work-related accidents. The law established the notion of responsibility “for risks” (without there necessarily being fault) and introduced the notion of social repair for the damage caused. The damage, i.e. the disability caused by the accident, refers to the loss of the ability to work. It was no longer seen as the consequence of individual behaviour, an individual’s fault, but as the product of a collective activity, and as such it should be dealt with by the community. This law thus broke away from the liberal tradition based on liberty and individual responsibility. By introducing the notion of collective risk, it marked a change in the way of thinking about and organizing social relations. The 1898 law pushed the judgment of individuals and individual responsibility into the background, and introduced the idea of a collective sharing of the costs relating to accidents at work. Henceforth, when the inability to work resulted from a work-related accident, it left the field of aid and charitable assistance. Work-related accidents as a social risk opened the road to collective repair, with the employer being obliged to take out insurance to guarantee its solvability. This notion of risk socialization was gradually extended to cover other risks. (Rosanvallon 1995).

In this way, the First World War extended this logic of risk socialization to include repair for maimed soldiers, by introducing a pension system. As in the case of victims of work-related accidents, the injuries incurred by a soldier on the front resulted in a collective activity. A special regime of social rights was created for maimed soldiers. In 1919, the French Ministry for ex-servicemen introduced an official scale for assessing disabilities, which was used to determine the levels of the pensions paid. Introducing access to the right to a military disability pension guaranteed by the State involved the disabled individual’s incapacity being assessed in accordance with this official scale.

From Financial Indemnification for the Damage Done, to Compensation for Impairment through Rehabilitation

Whilst war prolongs the notion of repair, it also changes it. The lack of workers – another consequence of war – led to the emergence of rehabilitation practices. Their objective was, by compensating for the disabilities, to enable invalid soldiers to return to work. To make repair, it was not enough to pay an indemnification, it was important also to compensate through physiotherapy and prostheses and achieve reintegration through work. These practices were gradually extended to invalid civilians, i.e. to people who have to live with the consequences of an impairment which cannot be cured. Following the place taken in the first half of the 20th century by chronic illnesses and health problems with long-lasting consequences (tuberculosis, and above all poliomyelitis; see Montès 2000, Oshinsky 2005), there is an ever increasing number of invalid civilians. For these people, professional insertion is an alternative to assistance. There has thus been a shift from simple financial indemnification (in relation to an injury) to compensation for disabilities through rehabilitation and physiotherapy, and on to professional reinsertion (Stiker 1999)².

The social insurance system which was set up in the first half of the 20th century (Join-Lambert, Bolot-Gittler, Lenoir & Méda 1997) contributes to the institutionalization of rehabilitation practices. In 1945, the creation of the Social Security system was the concretization of the socialization process described above. In its introduction, the founding text (edict of 4 October 1945) clearly states the objective of ensuring that all citizens have the resources with which to live in cases where they are unable to earn such resources through work. Several risks are covered by the social security system – invalidity, illness, maternity, old age, work accidents and professional illness. But the mechanism in place is the result of the insurance mechanisms developed in the first half of the 20th century, and only covers the workers and their families who are entitled to those rights through the contributions deducted from their salaries. A certain number of people are excluded from this system, and further notions of assistance will gradually be introduced to complete this system of insurance.

Disability as a Social Maladjustment requiring Specialist Intervention

The above history mainly relates to changes in the social treatment of adults with impairments; from the mid-20th century it encounters a parallel history which related to children and which, at that point in time, leads to the emergence of the notion of “social maladjustment”. This notion, which was to be replaced by that of disability, explicitly reveals the idea of a difference between the individual and the social norm, a difference which must be reduced through specialist interventions, hence the creation of a specific field. This notion has its roots in the concern, which appeared during the 19th century, for educating those who had until then been considered to be impossible to educate or incurable (Chauvière 2000, Gateaux-Mennecier 2000, Muel 1975, Pinell & Zafiropoulos 1978, Zafiropoulos 1981).

The first schools for impaired children were founded in Paris in the 18th century, for deaf children (the Institut des Sourds-Muets was founded by the Abbé de l'Épée in 1760) and for indigent blind children (in 1784, Valentin Haüy opened the first school which in 1786 was to become the Institution des Enfants-Aveugles; see Ravaud 2006, Weygand 1990). This concern for education was then extended to children considered to be idiots. In 1882, the Jules Ferry law made primary education obligatory for all children between the ages of 6 and 12. But very quickly, the school was finding it difficult to integrate those referred to as “abnormal children” (Vial 1990, 1991). These were children who were blind, deaf, idiotic, retarded or with motor deficiencies, and also children who were difficult, unstable, perverted, delinquent, etc. Hence the creation, in 1909, of specialized classes integrated into ordinary schools, and Ecoles Autonomes de Perfectionnement (independent specialized schools). This was the starting point for a specialist sector, one which would be built at the crossroads of school, asylum and legal institution; its objective, through the creation of a medico-educational system, would be to adapt to society all children who “clutter up” schools, or who, on the contrary, had until then been relegated to asylums,

correctional institutions, etc. Paedopsychiatrists would be asked to give diagnoses, to orientate the children (now qualified as “maladjusted”), and to develop educational and rehabilitative methods which would eventually allow such children to be put to work. (These experts examined the pupils at the school and separated the maladjusted children from the normal children, using IQ tests.) This sector was to involve a full range of professionals, institutions, establishments and specific, specialist knowledge (Ravaud & Lang 1998).

Institutionalization practices

The period between the two wars and the period immediately following the end of the Second World War saw the creation of the first associations for disabled persons (the Association des Paralysés de France was founded in 1933) and for children who were “maladjusted” (Barral 2007, in this issue). Their main objective was to take disabled persons out of hospices and psychiatric hospitals, and, through appropriate rehabilitation, to allow them to acquire the abilities they would need to reintegrate into society. Thanks to donations and bequests (real estate in particular), and with local political support, these associations were able to set up specialized educational institutions, special residential homes, workshops, holiday centres, etc. The creation of the French health and social security system allowed continued development. The state chose to delegate management of such institutions to associations, in return for the introduction of a daily price financed by the French health and social security system (accommodation and re-education costs were borne by the local community, with the institutions paying for the buildings).

At this point, we would like to stress the French specificity of these institutions. For the most part, they were of private initiative and were privately run (in an associative form), but functioned with public funding. From the 1950s, and above all in the 1960s and 1970s, the number of institutions was to increase considerably, but without any national planning, their creation being the result of negotiations between local associations and local political authorities which were more sensitive to the notion of leaving visible traces of their actions (sometimes qualified as a “stone and mortar policy”) than to the question of insertion into mainstream life. This specificity was also to mark the French associative movement: the notion of a “management” association was later to be considered as a brake on the rights of the people concerned, with the biggest associations finding themselves in a situation of conflict between their status as employers and their mission to represent disabled people (Barral, Patterson, Stiker & Chauvière 2000).

Towards a Disability Policy

We wish to retain two elements from this history: first of all, the emergence of the idea of repair related to that of invalidity. Invalidity became something

that was repaired by indemnification or a pension, and then compensated by prostheses and rehabilitation. An entire specialized sector – medical or medico-social – was gradually developed, with the objective not of curing, but of adapting adults or children to society, of enabling them to achieve integration through work, even if this meant temporarily removing them from society in order to rehabilitate them. The detour via an institution would then allow them to return to society. The second element is the change from assistance to social rights. Until the 19th century, cripples could benefit from assistance even though they were not allowed to claim it. Assistance was a moral issue. From the 20th century, following the changes described above, it became an obligation, a matter of legislation. A further step was taken with invalidity, interpreted as a social risk, and, as such, covered by a social insurance. Through a gradual extension of this logic, different systems for dealing with disabled persons were created in succession, but without replacing one another: the system for victims of work-related accidents, the system for maimed soldiers, for invalid persons under the French health and social security system, etc. The level of benefits available to individuals, which varies considerably depending on the system, depends on the origin of the disability. But certain persons with impairments (especially when since birth) cannot benefit from any of these systems and have to rely on assistanceship. These two elements constitute the bases for the notion of “handicap” that appeared in the second half of the century, and for the disability policy which was then put in place.

French Disability Policies since the Middle of the 20th Century: From one Form of Treatment to Another

“Handicapped Persons”: a Category-based Policy

The notion of “handicap” was originally used in sport, in horseracing; it designated the additional weight that the faster horses would be required to carry in order to give all runners an equal chance of winning. In France, the word then moved over to human beings, to signify a “disadvantage”; finally, in the second half of the century, it coexisted and ended up being substituted for all the terms used to designate people with disabilities, such as invalids, the maimed and the “maladjusted” (Stiker 1996). The use of the term “handicap” came about through a change in the representation and the modes of treatment of people with impairments, a change that was characterized, during the 20th century, by a connection being made between the notions of infirmity, risk and repair. The notion of “handicap” is used to designate a difference from a social norm, which is itself defined in terms of performance (mainly work-related), the difference being caused by the existence of an impairment. “Handicapped” people are people who differ from the average, from the social norm, who cannot do what average individuals can do (this notion of normality is founded in the statistical theory of Quételet and Galton; see Grue & Heiberg 2006), and who must therefore be adapted or readapted (Ebersold 1997). Use of the term marks the conjunction between

the field of adults (maimed soldiers, victims of accidents, invalids) and that of maladjusted childhood, although excluding one child category, that of delinquents. It appeared for the first time in an official text in 1957 (with regard to “handicapped workers”); it took over as the term to be used to describe a category covering all persons with an impairment, when in 1975 two laws were passed – the “orientation law in favour of handicapped persons” and the “law relating to social and medico-social institutions”.

These two laws extended the process of the socialization of responsibilities and the notion of social rights to all persons with an impairment, whatever the origin of that impairment might be. Article 1 of the orientation law thus states the national obligation to integrate “handicapped persons” into society. But these laws achieve this extension by organizing a category-based policy, i.e. by creating a broader category, that of “handicapped persons”. They institute the political, legal and administrative mechanism which allows one both to statistically define this category and to organize the system that aims to define the members, to grant them specific aid and to integrate them into society.

Indeed, the first law (orientation law) creates the status of “handicapped person”, a status which creates entitlement to certain rights (allocations, aid, etc.). This status covers everyone who, due to an impairment, whatever its origin, cannot integrate society in a “normal” manner, and who are therefore allowed to benefit from certain rights which facilitate their integration. The law provides for the following: it asserts the role of prevention and detection and disabled children’s right to education (it makes special education free and provides for compensation which allows families to cover extra costs relating to education and brought about by the child’s disability); as far as employment is concerned, it allocates the quality of “handicapped worker” with a view to facilitating professional insertion into a normal or sheltered environment and creates the right to guaranteed resources for the worker (this guarantee compensates for the loss in earnings due to the lesser output of people with lower work capacities); it also sets out methods of improving people’s social lives. Finally, it creates a specific system of social aid; this system does not remove existing systems of indemnification (victims of work-related accidents, disability pension under the health insurance system, maimed soldiers) but adds to them, to help those who have no other entitlements (“allocation for handicapped adult” which does not come from insurance, but from assistance). In addition, this system allows disabled persons who do not work to be protected by the French health and social security system. But whilst the orientation law creates the status of “handicapped person”, it provides no conceptual definition of disability. What a “handicapped person” is, in practice is defined and identified by regional commissions (one for adults, one for children) set up by the law.

Administrative commissions, made up of an equal number of representatives from the various administrations and interested parties concerned, have the responsibility of assessing the impairments of individuals. The first assessment is a medical one: a medical certificate and a medical assessment of the impairment constitute the entry ticket into the procedure. The commissions then compare the medical assessment and the official scale³ in order to

define a level of disability; this level will then determine what a person is entitled to and the type of cover. The allocation of a level of disability depends on the medical assessment; for example, a paraplegic person is allocated a disability level of 100%.

The second law, passed at the same time, covers the organization of social and medico-social institutions. It defines the missions of these institutions, and how they work. It led to the creation and organization of an autonomous medico-social sector, separate from the health sector (Bauduret & Jaeger 2002; see also the special issue of the *Vie Sociale* review, 2005). The emergence of this law led to a dual process. On one hand, as we have seen, associations promoted the creation of an ever-increasing number of institutions specializing in the care of disabled persons. On the other hand, the objective of re-integrating society is a difficult one to reach, and it has to be said that a temporary stay in an institution often becomes a permanent one. The expression “segregatory detour” has thus been used to qualify this movement of institutionalization (Ravaud & Stiker 2001). These numerous institutions have become places of living which are relatively apart from society, caring for people who, when it comes down to it, are considered to be unable to adapt to the society. From this comes the need to introduce legislation to standardize the organization and management of these particular institutions which are not healthcare institutions but places of living, of work, of learning.

These two laws and the resulting mechanisms created a category-based treatment for “handicapped persons”. The category is defined in a pragmatic manner on one hand, through references which state the characteristics of the typical representative of that category, and, on the other hand, through practices for the assessment and allocation of aid which compare each person and his/her individual characteristics, to those of the typical representative. Furthermore, this treatment leads to an objectivation of disability which becomes an inherent characteristic that is attached to the people in question, defining their identity, their status and their position. Each person is “labelled” as a member or non-member of the category, and this membership gives each person rights.

This category-based treatment led to a paradox. The integration of people (a national objective) was achieved by segregating them. This segregation was either implicit – people were integrated into the mainstream life through the specific status of handicapped person – or explicit – people were integrated via a specialist sector (Winance 2007). This paradox was increased by the time it took to apply each law. The second law came into force immediately, unlike the first, whose decrees of application came into existence either very slowly or, in some cases, not at all. This category-based treatment (treating individuals as members of a category) also led to spatial separation in the sense that it led to a distinction between spaces: the space for normality (for able-bodied people, for “the average person”) and the specialist sector space (qualified as the medico-social sector), the aim being for those who were “outside the normal space” to be able to re-integrate it. But, in the 1960s and 1970s, the category-based approach came into conflict with a universalist approach that was emerging from the question of accessibility.

The Question of Accessibility: the Emergence and Development of a Universalist Treatment

The question of accessibility arose in the 1970s in English-speaking countries and in the USA in particular. At this time, more and more disabled persons wanted to integrate into mainstream life, but they were encountering obstacles – architecture, lack of services. Ed Roberts, a disabled student at Berkeley, founded the first Centre for Independent Living, the objective of which was to provide disabled persons with all the services they need in order to live independently in society. Then came the creation of the Independent Living Movement, which highlighted accessibility as the main cause of the exclusion and dependency of disabled persons; in order to achieve independence for disabled persons, society had to be made accessible. The question of accessibility was then taken up by international organizations, and, in France, by certain actors confronting similar problems. The Association for Housing the Seriously Disabled (Association pour le Logement des Grands Infirmes, ALGI, founded in 1959), the initial purpose of which was, one by one, to rehouse disabled persons as they left rehabilitation or treatment centres, aimed to gradually fight for the construction industry to adopt accessibility standards (Sanchez 1997). Yet this principle of accessibility led to a change in the approach to disability, which was to be seen in the terminology used.

To highlight the problem of accessibility was to demonstrate that the disability, or rather the difficulties of a person with an impairment, were not due solely to the impairment itself (to individual characteristics), but also to the environment. In other words, there was a shift from the individual to environmental factors, and hence a related shift in the action being targeted: the target was no longer the adaptation of individuals, their normalization, but the adaptation of society, in such a way that society integrates the differences. The standard of reference had changed: it was no longer the able-bodied person, the “average person” who served as a reference, but “humanity”, representing all differences. This change in reference was accompanied by a universalization (opposed to the notion of category). Disability was no longer a constant that defined certain individuals as members of a given category, but a variable which depended on the environment. Thus the person in the wheelchair, the elderly person, the mother pushing her pram, the person carrying a pile of packages, all are confronted with similar difficulties: stairs, a door that is too hard to push open, a corridor that is too narrow, etc. With this approach, “we are all potentially disabled” and it is society which has to be radically changed. In the United States, this approach was pushed to its furthest by the Independent Living Movement (Zola 1989), a movement which fights for generalized accessibility in all areas of life. People then referred to universal design.

In France, the principle of accessibility is set out in the law of 1975, which, as we have already said, provided for an essentially category-based treatment. Furthermore, the law made implementation of this principle the responsibility of decrees and regulations, some of which were never passed. It set down no deadline and no penalty in case of non-application. In later years

this was to lead to a shift towards “category-based application” for accessibility, which involved making premises and transport accessible solely in the case of the effective presence of a disabled user and for his/her specific disability. This category-based interpretation of accessibility goes against its universal application, which would mean making the environment accessible for all disabilities and whether or not any disabled person is present. During the 1980s, due to pressure from associations and from international organizations (ONU, EEC) who adopted the principles of non-discrimination and of access by all people to all things, the principle of accessibility, under its universal interpretation, gradually prevailed (the law of 1991 on the accessibility of buildings open to the public).

During the 1990s, in France, this change was accompanied by the emergence of a new notion, that of “situation of disability”. Actors, especially associations, often referred to this when making their demands. This notion, by defining disability in an interactive manner, can have two meanings: the broader sense falls within the tradition of the universalist treatment; the other is contextual and leads to a more personalized treatment.

“Persons in a Situation of Disability”: a Shift Towards Personalized Treatment

The notion of “situation of disability” no longer defines disability as a difference from a social norm, nor as the consequence of the inaccessibility of the environment, but as an interaction. Disability is the result of an interaction between individual characteristics and an environment (Ravaud & Fougeyrollas 2005). This notion thus refers to an intermediate model between models qualified as individual and those qualified as social (Oliver 1996).

In the 1980s it was used in the scientific domain to stress the role of the environment (Minaire 1983). Then it was gradually taken on board by actors (associations in particular) in the field of disability. They used the notion in a dual sense, which sometimes led to a certain ambiguity regarding the approach that they were defending. At first they used it in support of the universalist approach; by defining disability in an interactive manner, they stressed the need to make society accessible by removing all barriers preventing the social participation of people with impairments. Then, a while later, there was a shift in accent; they stressed not only the idea of interaction, but also the notion of “situation”, defined as “context” or “circumstances”. “Situation” no longer referred to the general idea of the environment, but to a person’s own specific environment. This ambiguity exists in the official texts, as can be seen from a report from the Economic and Social Committee, “Situations of disability and living circumstances” (Assante 2000):

A brief reminder of the terminology will allow us to better understand the framework for this thinking. What do we mean by situation of disability? A situation of disability is always and solely the product of two factors, on the one hand a person referred to as “disabled” due to his or her impairment, be it physical, sensorial or mental, and on the other hand, environmental, social, cultural or even regulatory barriers which create an obstacle that the person cannot cross due to his or her particularity or particularities.

The existence of such situations prevents disabled persons from carrying on the everyday activities normally available to every citizen. The emergence of such situations creates a *de facto* discrimination . . . It is clear that the removal of such obstacles will not remove a person's impairment, but it will allow him or her, if certain conditions are met, to move freely throughout the city, to go to school, to his or her place of work, to his or her activities, etc. (Assante 2000:II-5).

During the various debates (both in parliament and in negotiations when drafting the texts, between associations and administrative and political actors) surrounding the creation of the new law, the notion of "situation of disability" had several functions. On one hand it was the instrument for personalized assistance and personalized ways of treating disability. "Situation of disability" refers to all the characteristics which make it a special, singular situation, *which is proper to the person in question*, different from other people's, and which needs to be analysed on a case-by-case basis in order to find a suitable solution. On the other hand, the notion of "situation of disability" is the tool allowing one to detach the disability from the person and to avoid any identification between the person and his/her disability; in other words, to avoid all stigmatization. The disability is no longer a state, it is interpreted as resulting from a set of environmental or individual characteristics which defines a situation and not a person. During the revision process for the law of 1975, disabled persons' associations stressed this point: during the procedures for allocating rights, it is a case of assessing a particular "situation of disability" and never a "handicapped person".

So whilst this notion maintains the idea of the role of the environment in the production of disability, it also reintroduces the role of individual characteristics, though in a completely different manner to that of the traditional category-based approach. The latter, which was based on a medical model, led to the objectification of disability through individual characteristics (impairment and incapacity), to attaching the disability to the person and to thus positioning the person within a status. Belonging to the "handicapped person" category was the condition *sine qua non* for rights to be granted. A given impairment corresponded to a given level of incapacity and gave entitlement to the same rights for everyone. The interactive approach, covered by the notion of "situation of disability", recognizes the role and the need to take certain individual dimensions into account, including impairment and incapacities in the emergence of a situation of disability; but these are not turned into objective and essential characteristics of the individual, they are seen in a relative manner, within a singular context. The purpose of the assessment is to identify all of the factors which play a role and which interact, in order to determine the action, targeting either the person or the environment or both, and to reduce the situation of disability without the individual being either defined or categorized; it is thus the situation which is defined, and not the person. In this case, the implemented action respects the principle of non-discrimination⁴.

The customized approach to disability that France is trying to set up with its new mechanism already exists in certain European countries. The

mechanisms grouped together under the generic terms of “direct payments” and “individualized funding” originate in the same logic (Askheim 2005, Carmichael & Brown 2002, Waterplas & Samoy 2001). The UK, Sweden, Norway, Belgium and Holland have introduced customized allocations (Waterplas & Samoy 2005). Its basic principle is to grant disabled persons money with which to pay for the aids needed for an independent life and compensating them for their needs, thus strengthening their control over their lives. Later on, we will see that the creation of a right to compensation is in some ways similar to these measures.

The Law of 11 February 2005 and the Debates that Surround it: a Crossroads at which the Different Approaches Meet

In the debates⁵ that surrounded the development of the new law and its decrees of application, and which now still surround the implementation of the new system, category-based, universalist and personalized treatments coexist. Each is defended by different actors, but they are sometimes all defended by the same actor who moves from one approach to another. Indeed, analysis shows that for some actors, the development of a disability policy and the reduction in situations of disability involve combining the universalist and personalized approaches. Opting for one to the detriment of the other would lead to solving only a part of the difficulties encountered by people in situations of disability⁶. Yet by putting the two approaches into a hierarchy, the actors give a different meaning to the policy being implemented. The National Consultative Committee for Disabled Persons, acting as a relay for disabled persons’ associations, made a priority of the universalist approach, with personalized solutions being used simply as a complement when generalized accessibility does not suffice to ensure a person’s full participation. The government favoured the personalized approach, which was easier to define in terms of cost. We will give two examples of these conflicts, the first being the debate on the definition of disability, the second being the debate surrounding the newly created right to compensation.

From a methodological point of view, our analysis in this section is based upon two types of data. Firstly, we observed a series of negotiation meetings in two committees which have always had and still have real influence. The first – the Committee for Entente between Associations Representing Disabled Persons and Parents of Disabled Children – is an informal group; it brings together the main associations in order to develop a common strategy to put before the government and government representatives, for whom it serves as a preferential mediator. The second – the National Consultative Committee for Disabled Persons (CNCPPH) – is a national committee with a direct link to the Minister responsible for disability. It has a dual mission: on the one hand to ensure that disabled persons participate in developing and implementing policies that concern them, and on the other hand, to assess the situation of these people and to come up with recommendations for improving them. It is therefore an official committee which, in its plenary form, brings together all of the actors concerned

(a French MP, a senator, people representing territorial collectivities, associations for disabled persons and their families, associations and organizations working in the field of disability, organizations for social protection, organizations carrying out research in the field of disability, unions and professional organizations for employers; representatives of ministries were also present, but were not allowed to vote). The CNCPH has a consultative voice for any project of law or decree relating to disability. As far as the 2005 law and its decrees of application are concerned, the opinion of the CNCPH must be obtained before any legislation can be definitively passed. Secondly, we gathered a corpus of documents produced by entities involved in the process (minutes from CNCPH meetings, intermediate versions of texts proposed by ministries, legislative texts, reports on disability policies made upon request from the government, exhaustive reports on parliamentary debates taking place in the French Senate and National Assembly – the two representative houses making up the French parliament). The two examples chosen for this part of our article – the question of the definition of disability and the question of the right to compensation – are based on a summary of the debates which took place in the different committees.

Disability: Between Category and Situation?

The 1975 law did not define disability in a conceptual manner, but solely in a pragmatic way, because it introduced local administrative commissions responsible for assessing people's levels of incapacity and, where appropriate, for granting the status of "handicapped person" and any related rights. This generates (and this is one of the major problems that the actors, the government, disabled persons' associations and professionals are trying to resolve) a vagueness and considerable heterogeneity in the attribution of the status of "handicapped person", depending on the commission. On the one hand, local variation in the assessments of incapacity levels, depending on the commission (commissions grant different levels of disability for the same medical and functional assessment), on the other hand, the emergence of the phenomenon of social exclusion which has led to an expansion, in practice, of the notion of handicap that was no longer based on the existence of impairments. In certain counties, commissions sometimes granted the status of "handicapped person" to people in poor health, unemployed and thus without resources, but whose incapacities were unclear. Faced with the disappearance of the boundary that was in France referred to as "social handicap", the government tried to unify the treatment of disabled persons with that of persons in situations of exclusion, to the detriment of the former. In February 2004, the government evoked the possibility of doing away with the allocation for a disabled adult (AAH) and of replacing it with the minimum income granted to social outcasts, the amount of which is lower than the AAH. During the revision process, there rapidly arose the question of adding a definition of disability to the law. But the stakes of the various actors were very different.

The government wanted to clearly define the area of application of the law, in order to avoid any drifts. Hence its preference for a category-based definition and its rejection of the expression “situation of disability”, which highlighted the risk of an extension of the target population and a grouping together of populations which had previously been separated (for example, “elderly persons” and “handicapped persons”). For disabled persons’ associations, the stake of this definition was threefold. First of all, they felt it was vital to get away from a category-based approach, seen as stigmatizing and excluding, which supposed a definition of disability and an organization of practices which do not turn disability into an objective characteristic of the person. They nevertheless wanted to maintain a specificity compared to other populations, in order to preserve certain advantages already gained (for example, the disabled adult allocation, the level of which was higher than that of other social aids). This specificity required disability to be defined in relation to the existence of impairments. Furthermore, within the field of disability thus delimited, disabled persons’ associations wanted the different systems of indemnification to be equalled out to suit the origin of the impairment⁷. Finally, in order to put the accent on a necessary universalist policy of generalized accessibility, the definition had to explicitly recognize the role played by the social and physical environments in producing the disability. Within the framework of the negotiations on the texts, during the plenary sessions of the CNCPPH, the three options were prioritized differently by the various associations of disabled persons. Some of them (the main association to be taking this stance is the Association des Paralysés de France, one of the biggest associations for the disabled in the country, defending the cause of those with motor impairments) saw the universalist approach to be the priority and defended the term “situation of disability”, whilst others (for example, the FNATH, Fédération Nationale des Accidentés du Travail, which has changed its name to Fédération Nationale des Accidentés de la Vie) preferred the other two options and a “category-based” terminology, whilst at the same time defending the notion of an interactive definition.

Despite its insistence, the CNCPPH, supporting the position held by the majority of the associations, was unable to win the day with its demand for the inclusion of a definition of disability as interaction. Yet the definition which was chosen is not a purely category-based definition, but the result of a compromise. It does not define a category by the objective characteristics of the individual members:

Art. L. 114. A disability, under this law, is constituted by any activity limitation or any restriction to participation in life in society to which a person is subjected in his or her environment due to a substantial, durable or definitive alteration to one or more physical, sensorial, mental, cognitive or psychological functions, or to a polydisability or to a disabling problem of health (Law of 11 February 2005).

Disability designates an activity limitation or a restriction to participation in life in society, and not the deficiencies of the individual. By making the solid link between disability and *substantial and durable deficiency*, the law clearly defines its field of application and, above all, distinguishes it from that

of exclusion or social disability. In so doing, it rejects the notion of interaction, the environment being integrated as a mere context. This reduction of the role of the environment to that of a simple context compromises the ambition of a universalist policy for generalized accessibility and brings personalized treatment to the fore, an objective which, as far as disabled persons' associations are concerned, should only be complementary. The assertion of the link between disability and impairment is made to the detriment of the recognition of the link between disability and environmental barriers, which is a disappointment to those who were hoping for a break away from the conceptions of disability that had prevailed until then. On the other hand, it satisfies the desire of the associations of disabled persons to preserve what they had already gained and to maintain their specificity in relation to the field of exclusion by diverging from a policy of insertion through work. By placing the accent on the notions of participation and citizenship, they give a broader definition of insertion, which can take place through work and school, but also through leisure activities, the exercise of one's political rights, etc. Hence their insistence, throughout the entire revision process, on the notion of "situation of disability", which from the outset places a person in society. Henceforth the objective is not to integrate or insert people in a situation of disability into society, for they are included from the outset, their difficulties being due to social interaction; as the title of the law indicates, the objective is "equal opportunities and rights, the citizenship and social participation of disabled persons"; society must ensure that people in situations of disability have the wherewithal to take an effective part in society, and that they have access to the same rights as everyone else⁸.

The Right to Compensation: Should Measures be Personalized?

One of the main principles of the new text is the distinction (previously blurred) between existence income (either from work or from national solidarity through social minima) and compensation for disability. The new law sets out a "right to compensation" in accordance with which people have the right to compensation for the consequences of their disabilities, which takes the concrete form of the allocation of compensation⁹. In the debates (parliamentary and CNCPPH) surrounding the drafting and determination of this right, there is a tension between category-based, universalist and personalized treatments.

In the text for the preliminary draft of the law presented by the government (December 2003) three conditions were set down for the right to compensation: age (exclusion of children under 20 and elderly people over 60), a minimum level of incapacity of 80%, and resource conditions. The combination of these three conditions for the allocation of compensation kept the latter within the framework of a category-based approach, the right to compensation being dependent on people belonging to a category the boundaries of which were age, level of incapacity and resources. The CNCPPH and disabled persons' associations immediately reacted and demanded the removal of the three conditions, as the right to compensation should be a

universal right granted to everyone “in a situation of disability”, whatever their age, resources or level of incapacity. In the final text, passed in February 2005, the three conditions that had originally imposed were removed (albeit with transitory periods, especially with regard to the removal of age barriers), as demanded by the CNCPPH¹⁰.

Furthermore, the allocation of compensation was not seen as a set allocation granted in accordance with individual characteristics (i.e. the objective characteristics of an individual inasmuch as they result from a comparison of the individual with a specific grid), but as something to be adapted to a given person and his/her personal situation. The objective was no longer to compensate for disabilities, but to meet needs, needs which were specific to each individual because they depended on his/her way of living and life project. These needs were assessed by a multi-discipline team which, on the basis of an overall examination of “the situation”, came up with a personalized compensation plan. But whilst the law indicated the principles to be followed, it did not define the concrete forms of application, which were to be set out in decrees. Yet during the drafting of these decrees and the creation of the new system, lively new debates took place, particularly regarding the tools used to make this assessment. These debates once again brought disabled persons’ associations into conflict with the government, within the framework of the works carried out by the CNCPPH. A new tension has arisen between the need to develop standardized criteria to ensure equal treatment throughout the country, the desire for personalized treatment and the refusal to categorize. Disabled persons’ associations are once again stressing the idea of “situation of disability” which allows them to distinguish between the category-based treatment that has existed so far, and their demand for personal treatment. This notion shows that the assessment is not of the person, of his or her individual characteristics, but of the person’s situation of disability, of the specific interaction that the disability creates, thus preventing the person from living in society and achieving his or her life project.

Conclusion

Analysis of the revision process for the 1975 law and the debates that surrounded it shows the existence of a current tension between three approaches to disability that emerged at different moments in history. The law and the policy which were implemented give concrete form to these tensions. The category-based approach is defended by the government and certain disabled persons’ associations; for the former, it allows a defined population to be targeted, thus making it possible to control public expenditure; for the latter, in a period of economic uncertainty it allows people to keep the rights which have already been acquired. The partial maintenance of this approach, in particular through the imposition of eligibility criteria which create entitlement to compensation, can be interpreted as being due to the weight of history. As we pointed out in the first part of the article, in France this approach was the basis for the system of social

protection. Above and beyond this maintenance, the analysis revealed a conflict between two more recent approaches to disability: the universalist approach (in existence since the 1970s) and the interactive and personalized approach (which took form in the 1990s and 2000s). The integration of these two approaches into the law and policy marks an evolution in the representations and treatment of people with disabilities. These evolutions follow those already seen in English-speaking countries and abroad (Albrecht 2000, Ravaud 2001, Scotch 1988).

The notion of “handicap”, defined as a difference from the social norm due to the existence of an impairment, linked the disability to the individual and objectified the disability by leading to the definition of a category of persons. The other two approaches, universalist and interactive, detach the disability from the individual, either in order to link it to the environment or to place it within an interaction. They henceforth open up the possibility of a non-category policy, which does not presuppose that people be labelled in order to define an action, an intervention – in a logic of non-discrimination. They thus open up the possibility of a change in reference and in norm in order to assess and define “disability” (Winance 2007) inasmuch as the norm is no longer predefined and determined, but is simply the stake of negotiations. As we briefly mentioned, the question of the centrality of work as an unavoidable road to insertion is under discussion (Ville & Winance 2006). What the notion of “citizenship” covers is not defined, and must be defined, virtually on a case by case basis, by the individuals concerned, the people around them and by the professionals who make the assessment, in what the law calls a “life project”; this will vary considerably from person to person. Finally, analysis of the debate and the policy shows a specificity of the policy in France. The latter in fact results from a desire to keep the last two approaches together. The level of this desire depends on the actor. At the same time – and this will be the object of more detailed research – the way in which each actor links and prioritizes these two approaches leads to different representations of the individual, of the society in which he/she lives, of the relationship between the individual and society.

Notes

¹ It should be noted that the development of the “general hospital” did not homogenize the field of assistance. In the 19th century in France there was a great diversity of establishments, some old, some modern: hospitals only accepting people who were ill, hospices for old people, for the crippled, the incurable and orphans, general hospitals with mixed populations. There were also charity offices (Bauduret & Jaeger 2002).

² Rehabilitation practices have often been interpreted in the sense of a reduction in difference and an alignment with the norm of able-bodiedness. Without denying this aspect, we wish to underline two arguments. Firstly, these practices cannot be understood independently of the contexts in which they occurred. For the persons concerned, in the middle of the century these practices represented a real opportunity, that of being able to leave the hospice or asylum. We have also shown through ethnography that current rehabilitation practices will allow actors to work on the norm and to transform the norm of validity (Ville & Winance 2006, Winance 2006).

³ In 1993, the “official scale for the assessment of the disabilities and impairments of handicapped persons” replaced that used for ex-servicemen since the First World War. “This guiding scale gives a

level or a level bracket for the incapacity caused by each impairment in terms of an assessment of how said impairment affects day-to-day and social life.” (Sanchez 2005:100).

- ⁴ Of course, one might argue that this process also leads to the creation of a “persons in a disability situation” category. But unlike the “handicapped person” category, which, due to the assessment procedure is very homogenous, the “persons in a disability situation” category is likely to show high heterogeneousness and high variability over time. Furthermore, the fact of belonging to a category (the recognition that one belongs to this category of individuals) does not mean one will be granted rights. The category can only be obtained a posteriori through a census and grouping together of all persons having obtained certain rights. Category-based treatment is based on a priori categorization.
- ⁵ Such debates have been numerous and varied, involving different actors. We use the term here in a generic manner, to designate all such debates: debates which took place in the Conseil National Consultatif des Personnes Handicapées (see below), parliamentary debates, one-off debates such as when the government organizes themed meetings, etc. Later in the article we will give details of the venue for each debate mentioned. Finally, it should be noted that this debate received very little media coverage, particularly in the daily press, which only described, essentially in an informative manner, the key moments of the revision processes (the move over to the French National Assembly for example). We did not however carry out a systematic examination of the press, which would certainly have allowed a more detailed analysis.
- ⁶ During the numerous debates surrounding the evolution of the social model in Great Britain, some researchers (women) raised this question: the radicalization of the social model leads to some people being unaware of the problems that certain persons are facing, by denying and suppressing the importance of the individual experience of disability (Crow 1996, French 1993).
- ⁷ We must remember that the law of 1975 had maintained the different systems of indemnification whilst at the same time creating a new one, relating to assistance. This question of equalization is currently being debated within the framework of a project to standardize the levels of the disability pension (regime governed by the French health insurance system) and the AAH (“assistance”).
- ⁸ We believe that the definition of disability, as set out in the 2005 law, perfectly fits the analysis of laws proposed by P. Lascoumes. Basing himself on an analysis of laws in the field of the environment, he demonstrates in particular that “Every legal system is simply an adjustment, to varying degrees of stability, of diverging and sometimes contradictory social interests, under the arbitration of public authorities” (Lascoumes 1995:399).
- ⁹ The allocation of compensation finances five types of expenditure: 1) human aid, 2) technical aid, 3) adaptation of place of living and/or vehicle, along with any additional transport-related costs, 4) specific (i.e. the purchase of nutrients to improve a regime) or exceptional (one-off disability related) costs relating to the disability and not covered by other systems charges, 5) allocation and maintenance of animal assistance. It should be noted that, so far, only the decree relating to compensation for life at home has come into effect. A decree relating to compensation when living in an institution should be coming into effect soon.
- ¹⁰ Eligibility criteria are nevertheless still in force, making it possible to decide who is or is not entitled to the allocation of compensation. But these criteria no longer lead to an objectivation of individual characteristics. In order to be entitled to the allocation of compensation, one must show absolute difficulty in doing one activity or serious difficulty in doing two activities. The activities taken into consideration are those relating to mobility, looking after oneself, communication, the general ability to situate oneself within the environment and protect one’s interests (i.e. to situate oneself in time and space, to ensure one’s own safety) and one’s relationships with others. A commission (commission of rights and autonomy) then grants or refuses an allocation of compensation based on the above criteria.

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